

Dear Chairman Longbine and Members of the Insurance Committee,

Firstly, I would like to thank you for your service to Kansas and for taking the time to consider my testimony. I am writing in support of PANS/PANDAS insurance coverage (HB 2110).

I was 11 when I contracted the strep infection that triggered my PANDAS, though no one but my mother knew. If I knew how many doctors my mother called, emailed, or visited, I would tell you. The only memories I have of these appointments are that they were often long, far away, and mom was always disappointed afterwards. No doctors in our area would support her diagnosis, of which she was completely certain. We eventually ended up visiting Dr. Kobayashi in Omaha, NE. Although he could not reverse the damage that was done by the disease, he was the only one who could confirm my mom's theory that her 11-year-old daughter developed tics, severe depression, and a debilitating panic disorder from an autoimmune response to a strep infection. Dr. Kobayashi put me on antibiotics to avoid a second infection and gave my parents the support they needed to navigate the years ahead.

Most of my childhood memories were lost as a result of PANDAS. The few memories that remain are painful. I remember feeling that my brain was attacking me, and it would make me scream, which frightened my little sister. I remember kicking and screaming at the top of the stairs, confused and unable to stop the tics. I have one memory of crying with my parents at the kitchen table because we didn't know what else to do. My mother used to tell me that she would give anything in the world to make it all better. I understand the nightmare of living with PANS/PANDAS, but I will never truly understand the horror that my parents experienced in those years. Although my initial symptoms eventually stopped, those moments will forever live in the memories of my parents.

In the years since the infection, I have lived with an anxiety disorder accompanied by frequent episodes of memory loss. I have lost my ability to concentrate heavily on things like reading or homework assignments. A recent MRI revealed the regions of my brain that incurred damage, presumably by PANDAS. These results align with those described by Zheng et al. in the paper cited below (which I found to be quite interesting).

Now, I am 22 years old. I graduated high school with a 4.8 GPA and a near-full ride to the University of Kansas. I participated in the marching band, earned University and Departmental honors, and graduated one year early (despite changing my major eight times). After graduating, I decided to stay at KU and pursue my master's degree. I am currently in the first year of my master's program at KU, where I study genetics. Alongside my lab-specific thesis project, I am involved in a collaborative out-of-state project that aims to pinpoint the genes associated with PANS/PANDAS. I am hopeful that we will soon be able to treat at-risk children with antibiotics before they are exposed to the bacteria that triggers the PANS/PANDAS autoimmune response. If I am able to contribute even one shred of evidence for the purpose of preventing PANS, I will consider my career a success.

I have been hearing and reading about PANS-based laboratories along the coasts. Every day, more doctors are becoming PANS specialists. The frequency of PANS-specific publications in the past decade is evidence that PANS education and recognition is spreading. Diagnoses, however, are only useful if there is available and affordable treatment. I was lucky enough to have parents that could afford to find the answers they needed; many are not so lucky, and many require more treatment than I did. The passing of HB 2110 will not just help Kansas families with the financial burden of the disease; it will establish a culture of PANS/PANDAS education in our state.

A decade ago, my mother recognized the reality of PANS disorders and fought for them to be recognized by other scientists. Now, thanks to her and Dr. Kobayashi, I am here to fight for the protection of Kansas families against such disorders. I hope that what I have shared with you is evidence enough for you to support HB 2110 as it is discussed in the Senate chamber.

I deeply appreciate the time you have taken to read my testimony. If you have any questions or would like to discuss further, please contact me at (913)-515-7705.

Sincerely,

Noelle Schlenk

Works Cited

Zheng J, Frankovich J, McKenna ES, Rowe NC, MacEachern SJ, Ng NN, Tam LT, Moon PK, Gao J, Thienemann M, Forkert ND, Yeom KW. Association of Pediatric Acute-Onset Neuropsychiatric Syndrome With Microstructural Differences in Brain Regions Detected via Diffusion-Weighted Magnetic Resonance Imaging. *JAMA Netw Open*. 2020 May 1;3(5):e204063. doi: 10.1001/jamanetworkopen.2020.4063. PMID: 32364596; PMCID: PMC7199120.